



Fetal Alcohol Syndrome Update

Winter 2002

Office of FAS, Department of Health & Social Services, State of Alaska

FASD Curriculum Development Project Underway

The Fetal Alcohol Spectrum Disorders (FASD) Curriculum Development Project is fully staffed with the hiring of Sandy Kleven as trainer. She joins Sally Timp, project assistant, who has been on staff since August. The FASD Curriculum Development Project, funded through the DHSS Office of FAS, is housed at the Family and Youth Services Training Academy, UAA School of Social Work in Anchorage.

The Curriculum Development Project will provide assistance and training to service providers who serve clients affected by FASD. The project is a partnership that includes the DHSS Divisions of Family and Youth Services, Public Assistance, and Juvenile Justice, the Department of Corrections, foster care and residential care programs. The importance of developing this type of training has been demonstrated by the difficulty in meeting the needs of clients affected by prenatal exposure to alcohol and the resulting disabilities. Behavior exhibited by these clients — impulsiveness, failure to learn through consequences, risk taking, forgetfulness — can be misinterpreted as willful misconduct with unfortunate results. By educating service providers about the potential limitations caused by this disability, expectations will be more realistic and interventions to insure better outcomes can be presented. The first “test” of the new FASD training will be to DFYS Supervisors in March 2002.

Sandy comes to the program from Bethel where she worked as a children’s mental health clinician for several years and then as a training coordinator. She holds a Masters Degree in Social Work and is licensed as a clinical social worker. Since Sandy has lived for 15 years in various parts of rural Alaska, she is struggling to adjust to the city. “I forget to lock my car doors; my top speed is 45 mph and I am suspicious of tap water. I give phone numbers in 4 digits only and I call state agencies and say, “This is Sandy” with the expectation that they’ll know who I am.” We extend our most sincere welcome to Sandy and know she will get the hang of “city life” very soon!



Sandy Kleven and Sally Timp, staff of the FASD training project.

Happy New Year!

The Office of FAS wishes everyone a happy, healthy and productive New Year! As we say good-bye to 2001, we look back on all the activities, successes, challenges and energy that has been focused on fetal alcohol syndrome and the state’s FAS agenda. Much has been accomplished—awareness has increased, providers have been trained, community-based diagnosis is happening—and yet, much still remains to be done. We are excited at the prospect of another successful year, moving us closer to reducing the incidence of FASD in Alaska and to improving the lives of those individuals already affected by prenatal exposure to alcohol. Thanks for all your help and support in 2001.

Features

Spotlight on FAS Innovative Grantees	3
FAQ: Do Children Outgrow FASD?	5
FAS Community Team highlights	6
Dates to Remember	8



Commissioner

Jay Livey

Program Manager

L. Diane Casto

Community Coordinator

Heidi Brocius

Grants Administrator

Jenny Huntley

Administrative Assistant

Sherrie Stears

Publications Specialist

Peter Anderegg

Research Analyst

Kate Heitkamp

Student Intern

Benjamin Shier

POB 110609

Juneau, Alaska 99811-0609

Phone: (907) 465-3033

Toll-free: (877) 393-2287

Fax: (907) 465-1189

www.hss.state.ak.us/fas/

fas@health.state.ak.us

Four New Communities Join Team Network

In October, the Office of FAS selected four (4) new communities to become part of the Alaska FAS Multidisciplinary Community Team Network. Three community teams from Sitka, Kotzebue and the Mat-Su Valley will receive training at the University of Washington in February of 2002 and the community team from Tok will be trained in fall of 2002.

Each community submitted a team proposal that indicated true community collaboration, addressing community readiness, incidence of alcohol-related issues for their community, collaborative efforts in development of team, team composition and team member's long-term commitment. Each proposal scored very high and reflected the need for increased FAS services across the state of Alaska. Following their Seattle training, the Office of FAS will provide each team with technical assistance in developing a clinic model, getting the team ready to begin client services and assisting them in developing FAS community education programs. With the addition of these four (4) teams, the FAS Team Network includes a total of 15 community-based FASD diagnostic teams, serving Alaskans from Barrow to Ketchikan! For contact information for the new teams, call the Office of FAS at (877) 393-2287.

Governor's FY2003 Budget Continues Focus on Healthy Alaskans

The health and well-being of Alaska's citizens continues to be a strong focus of the Knowles-Ulmer Administration, as evidenced in the recently announced fiscal year 2003 state budget. At the FAS Summit 2001 on November 15, Governor Knowles announced his request for \$7.6 million to fight the effects of alcohol, including prevention of all alcohol-related birth defects. In his remarks, Governor Knowles stated that Alaska has one of the highest known rates of FAS and ranks first in the nation for alcohol-related deaths. The rate of alcohol dependence and alcohol abuse in Alaska (14 percent of the population) is twice the national average.

The Governor's alcohol initiative includes \$3 million to reduce the waiting list for alcohol treatment; \$867,000 to hire more rural substance abuse counselors; \$470,000 to increase/enhance the Alcohol Safety Action Program in 11 Alaska communities; and \$2.5 million to improve alcohol treatment for juveniles, women with children and criminal offenders with children.

In addition, the Governor's Smart Start/Strong Future budget initiative will continue the progress begun under Smart Start. The initiative has three goals: improve child health; keep children safe; and help children succeed. The Governor has requested \$9.2 million in general funds to prevent infant abuse among young people, improve children's overall health, prevent suicide, protect and support children in state custody, increase the daily compensation rate for foster parents, improve child care quality and promote early childhood literacy.

The Governor's FY2003 budget will make great strides in improving services to all families and individuals dealing with the affects of prenatal exposure to alcohol and enhances the progress being made to prevent future FASD births.

This publication is funded by the U.S. Department of Health and Human Services, Substance Abuse and Mental Health Services Administration. Grant #5UD1 SP09198-02.

Spotlight on FAS Innovative Grantees

Each quarter the FAS Update will highlight three (3) of our FAS Innovative grantees. By sharing information and progress about our grantees we hope to generate partnerships, collaborations and ideas for continuing the state's progress to prevent FASD and to improve lifetime outcomes for individuals with this disability.

Safe Inc.

SAFE, Inc., a domestic violence, substance abuse, and child abuse and neglect agency in Dillingham is using their FAS Innovative Grant to support prevention efforts in their community. In developing their project, SAFE examined the barriers that prevented women and children from participating in post-treatment services and other sobriety efforts, and noted that child care and transportation were two major obstacles in getting women to attend. Through the use of FAS grant funds, SAFE, Inc. is able to provide child care and rides to women interested in attending groups and other support services who wouldn't otherwise be able to attend. SAFE has also taken the additional step of training advocates and staff about FASD, and have used this new information about prenatal alcohol exposure to change their approach in working with women who may also be affected by FASD. For more information about SAFE's FAS project, contact Ginger Baim at (907) 842-3257.

Rural Community Action Program

Another exciting Innovative FAS project is being coordinated by Rural Community Action Program (RuralCAP) in Anchorage. Last year RuralCAP's energetic staff developed, produced and distributed 4 posters promoting healthy decisions in early pregnancy. The posters have been distributed far and wide, including the SAMHSA office in Rockville, Maryland where they are proudly displayed. Additional products being developed, using the poster images, include a 2002 calendar, post cards and note cards. Year 2 plans are currently underway for the development of an informational video and a school-based curriculum for teachers interested in educating their students about the risks of drinking during pregnancy. RuralCAP has solicited statewide input for all of its FASD projects, and uses its statewide system to distribute materials across the state. For more information about RuralCAP's project or for copies of their great poster series contact Marian Estelle at (907) 279-2511.

Volunteers of America

Programmatic staff at Volunteers of America, Alaska (VOA) are using their Innovative Grant funds to offer support to families affected by FASD through activities, information and resource sharing. They are currently gearing up for their first winter family camp at Solid Rock Camp in Soldotna January 18-21. This is the first winter camp for the VOA project, which has traditionally operated a summer FAS family camp only. Innovative grant funds have allowed the agency to expand to operating the two camps, and to provide travel scholarships to ensure that families from across the state are able to participate in the support, fellowship and fun that family camps provide. For more information about the upcoming family camp or the VOA FASD project contact Pat Cochran at (907) 279-9646.

FASD Training in Seward

The Chugachmiut Healthy Start Project and Frontier Community Services of the Kenai Peninsula are co-sponsoring training by Debra Evensen in Seward, January 25 and 26, 2002. The training is titled *STEP BY STEP, Trying Differently—Not Harder—with the Fetal Alcohol Affected Child*. The workshop is being offered at no charge and one college credit is available (with completion of the training, homework and payment of college fees). The training will begin at 4:00 PM on Friday the 25th and will end at 5:30 PM on Saturday the 26th at the Hotel Edgewater in Seward. Special conference rates are available for those wishing to spend the night at the Hotel Edgewater. To register, please call Holly Mercado, Frontier Community Services at (907) 262-6331 or 800-819-8194.

Winter FAScinating Families Camp

For all families raising children with FASD, a fun winter family camp will be held January 18-21, 2002 at Solid Rock Bible Camp in Soldotna. Volunteers of America (VOA) is hosting this first-ever winter family camp, to provide families raising children with FASD time for relaxing, having fun and finding support and friendship with other families!

Camp activities will include skating, sledding (even a rope tow up the hill!), snow-shoeing, and possibly dogsled rides too! In addition, Diane Malbin, a national expert on raising children with FASD, will be the guest speaker. To ensure some uninterrupted time for parents to hear Diane, network or just relax, specified periods of respite childcare will be available throughout the weekend.

For information call Pat at (907) 279-9646 or email at voa-allstars@voaak.org.

FASD Media Campaign Development Begins

The Office of FAS has selected Nerland Agency, an Anchorage-based media firm to develop our statewide multi-media campaign to change public perception about the dangers of drinking alcohol during pregnancy and the resulting birth defects. Nerland Agency was selected through a competitive bid process, with eight other agencies competing for this exciting project. We are working jointly with the Divisions of Juvenile Justice and Alcoholism and Drug Abuse to include messages about underage drinking and youth prevention efforts, expanding our campaign to reach the widest audience possible. The campaign will include a variety of messages that will be geared towards all ages, cultures and regions. We are anxious to begin work on this project and will utilize data from our "knowledge, attitudes, beliefs and behaviors (KABB)" survey (being conducted in early 2002) to target specific areas of public education needs.

The first year of the campaign will focus on TV, radio and newspaper ads that inform women and their families about the dangers of drinking during pregnancy and minor consumption. Several focus groups will be held across the state to determine the effectiveness of the developed messages. A repeat of our "KABB" survey will be done at the end of our five-year project to determine the success of the campaign and the change in public attitude and information. Keep an eye out in your local media for ads to begin airing in late summer.



FAS Summit Overwhelming Success



Former DHSS Commissioner Karen Perdue catching up at the Summit with new Commissioner Jay Livey.

treatment services.

Both Governor Knowles and former DHSS Commissioner Karen Perdue received awards recognizing their steadfast commitment to the state's FAS agenda, in addition to awards presented to Cheri Scott, Anchorage and Debra Evensen, Barrow, for their outstanding work in the area of FASD in Alaska. The FAS Parent Support Group presented a special "Thank You" award to Representative Fred Dyson, Eagle River, for his dedication to FAS issues. The Summit closed with a Parent Panel, exploring the joys, challenges and strategies of raising children affected by prenatal exposure to alcohol.

A big thank you to our Summit Work Group, who helped set the agenda, speakers and workshops beginning last summer, and a special thanks to the Office of FAS staff who spent MANY hours pulling together all the details for the Summit, including the great FAS Summit Resource Book, a favorite among Summit participants.

The FAS Summit 2001—Beyond Diagnosis: Grief, Healing and Community Collaboration, was filled beyond capacity with over 480 participants attending this two-day event. Participants came from across the state and represented a broad spectrum of disciplines including educators, attorneys, social workers, foster parents, correctional officers and many, many others.

Carolyn Hartness, the Summit's keynote speaker opened the conference with a challenge that all of us approach FASD with the sensitivity and understanding needed to address community and individual grief and healing, as a critical element to truly preventing this devastating disability. Governor Tony Knowles addressed the conference, calling for an increase of over \$7 million in State funds to combat the effects of alcohol abuse, including increased



A capacity crowd of over 480 participate in FAS Summit 2001!

FAQ: Do Children Outgrow FASD?

People often ask, or often assume, that fetal alcohol syndrome is a condition associated with children, a condition that is “outgrown” as the child grows into an adolescent and then an adult. Perhaps because of the word “fetal” or because of the apparent changes in facial features as a child enters puberty, but, the reality is that fetal alcohol syndrome (FAS) and all other birth defects resulting from prenatal exposure to alcohol are permanent.

FAS refers to a permanent birth defect syndrome caused by maternal consumption of alcohol during pregnancy. The condition is characterized by pre-and/or postnatal growth deficiency, a specific set of minor facial anomalies, and prenatal alteration in brain function, causing a variety of central nervous system disorders that can include neurological abnormalities, delays in development, intellectual impairments, learning and behavior disabilities and in some cases mental retardation.

Alcohol is a teratogen that can cause fetal malformations in the form of permanent structural changes to the brain, to cells and to normal growth and development patterns. Once the malformations have occurred, the damage is irreversible.

But, with all this said, it does not mean that the outcomes for an individual affected by prenatal exposure to alcohol can not improve with time, with services and with appropriate structures and interventions in place. Like all disabilities, improvements can be made in how a person adjusts to their disability, what types of services are provided to accommodate the disability and what kinds of ongoing trainings and supports are in place to help the individual be successful. This is why it is so critical that all children with this disability get an early diagnosis, that appropriate service plans are developed and that those services providers and caregivers working with this disability truly understand the nature of FASD and the impact on an individual’s ability to function. With diagnosis, specialized services and a supported living environment, individuals with all fetal alcohol spectrum disorders can be successful living with their disability.

Student Intern Joins FAS Staff

In late November, Benjamin Shier joined the staff of the Office of FAS as a part-time student intern. Benjamin, a senior at Juneau Douglas High School, is skilled in computers and web page design and has spent the last month updating our current site and assisting with planning for the new design our web page will take in early 2002. Ben is responsible for keeping our site current and up to date with training and resource information. Also, over the next six months we will be adding some new features such as online video check-out and services provided to our grantees and teams. We welcome any feedback you may have on our site, including suggested topics and information, and encourage all to submit nominations for our web exclusive “Special People” page. Questions about the Office of FAS website should be directed to Jenny Huntley at (877) 393-2287 or (907) 465-3033.



New FAS Prevalence Data Released

New prevalence data has been released from the Alaska FAS Surveillance Project. A project of the DHSS Division of Public Health, Section of Maternal, Child and Family Health, the Surveillance Project is part of a collaborative effort with the Centers for Disease Control and Prevention (CDC) and four other states; Arizona, Colorado, New York and Wisconsin.

New data indicates a FAS prevalence rate of 1.4 births per 1,000 live births and a rate of 12.6 per 1,000 live births for those at risk of having an alcohol-related birth defect other than FAS. While prevalence rates for Alaska may be higher than for other state populations, our data indicates there are about 14 new cases of FAS per year and about 126 cases of children born at risk for alcohol-related birth defects.

For a more in-depth analysis of these and other findings of the Alaska FAS Surveillance Project, see the October 2001 Family Health Dataline, published by the DHSS Division of Public Health. Issues of the Dataline are available by calling 907-269-3400.

CSAP Launches FAS Center for Excellence

In the fall of 2001, the Center for Substance Abuse Prevention (csap) launched the FAS Center for Excellence to help the nation prevent FAS and improve the quality of life for individuals and families affected by this debilitating condition. The new Center will provide a national focal point for FAS information and resources, promoting successful, evidence-based programs to prevent FAS and identify ways to support individuals and families already affected. The FAS Center will also coordinate all CSAP-funded FAS efforts throughout the country, including Alaska's 5-year FAS Project. The FAS Center will provide assistance in an array of shapes and sizes: experiential workshops, literature, how-to manuals, videos, web sites, national conferences and other innovative media. Its primary target is those needing the information the most—people working on the front lines, who want to make significant differences in the lives of mothers at risk of delivering FAS babies and people already affected by the condition.

The FAS Center for Excellence will be guided by a national Steering Committee composed of representatives from federal, state and local agencies, and organizations with expertise and interest in FAS. The Steering Committee will include two Alaska representatives: L. Diane Casto, Office of FAS Program Manager and Karen Perdue, former DHSS Commissioner. Within the next month the FAS Center for Excellence will have a web site and a toll-free phone number that we will pass along in our next newsletter.

FAS Training for Residential Care Providers

The Alaska Association of Homes for Children, through a grant from the Division of Family and Youth Services, is offering a series of workshops titled: *Understanding Fetal Alcohol Syndrome: A Class for Direct Care Staff and Other Human Service Professionals*. The training will provide an introduction to fetal alcohol syndrome (FAS) including characteristics and developmental issues; behavioral issues; intervention strategies; and resources. It is designed specifically for people in residential children's facilities or other programs dealing with FAS-affected children and adults. Presenters for the 2-day training are Mary Lou Canney, Resource Center for Parents and Children in Fairbanks and Maureen Harwood, University of Alaska Fairbanks. Training will be held in Bethel, Anchorage, Sitka, and Fairbanks. While the Anchorage and Fairbanks trainings are already full, there is still space in Bethel and Sitka.

◆ Bethel, January 22–23, to register call Jody Sleppy at (907) 543-2846, ext. 301

◆ Sitka, February 6–7, to register call Pam Robinson at (907) 747-3682

Thank you to Sue Pope for coordinating these great training events, increasing the FASD skills and knowledge of Alaska's residential care providers!

FAS Community Team Highlights

The Kenai/Soldotna FAS Community Diagnostic Team, housed at Frontier Community Services, has been an active team since receiving training at the University of Washington in February of 2000. Since holding their first clinic in December of 2000, more than 80 people, ranging in age from 11 months to 43 years have received diagnosis. The team provides diagnostic service throughout the entire Kenai Peninsula, and continues to facilitate diagnosis and follow-up support for families from a number of communities around the Peninsula. In addition to conducting monthly diagnostic clinics, the team facilitates community outreach and education. Last year the team sponsored two community-based trainings featuring national and statewide speakers. Another training, presented by Debra Evensen, is slated for January 25th and 26th in Seward. For more information about the diagnostic team or the upcoming training, contact Margaret Parsons-Williams at (907) 262-6331.



Kenai Peninsula FAS Diagnostic Team.

New Reports Released

Three recently released reports highlight our state's problems with alcohol use and abuse, the economic cost associated with substance abuse, the need for increase treatment options and the progress being made to address alcohol issues including fetal alcohol spectrum disorders.

Economic Costs of Alcohol and Other Drug Abuse in Alaska, Phase Two.

Prepared for the Advisory Board on Alcoholism and Drug Abuse by McDowell Group, a research-based consulting firm in Juneau and Anchorage, with a grant from the Alaska Mental Health Trust Authority. The report, released in November, indicates the negative economic impacts of alcohol and other drug abuse amount to about \$614 million a year in Alaska—\$453 million per year related to alcohol abuse and \$161 million a year related to other drug costs. Copies of the report are available by calling (907) 465-8920 in Juneau or (888) 464-8920 statewide or from the ABADA web site at www.abada.com.

Substance Abuse Treatment Needs of Alaska's Newly Incarcerated Prisoner Population Prior to Incarceration: Final Report.

This report was prepared by North Charles Research and Planning Group (NCRPG), under contract with the DHSS Division of Alcoholism and Drug Abuse, in cooperation with the Department of Corrections. The study concludes the "greater availability of [treatment] services might have reduced the consequences of the respondents' substance use disorders and in some cases perhaps might have prevented the crimes that brought these inmates into custody." Copies of this report are available by contacting Julie Penn at (907) 465-1612 or visiting the DHSS web site at www.hss.state.ak.us.

2001 Status Update: Alaska's Response to Fetal Alcohol Syndrome.

This is the annual state report, highlighting the state's response to fetal alcohol syndrome and issues related to drinking during pregnancy. This year's report provides a year-one overview of the 5-year federal SAMHSA grant, an update on project activities and progress made through community-based initiatives and partnerships. Copies of the report are available by contacting the Office of FAS or visiting our web site at www.hss.state.ak.us/fas/.

Diane Malbin Video Series Available

Diane Malbin, an FAS trainer and writer, has produced a 4-part lecture video series dealing with FAS. The first video discusses FAS basics and diagnostic criteria. Video two describes and illustrates common learning and behavioral characteristics. The third lecture in the series discusses behaviors and overlapping diagnosis. The fourth and final video touches on barriers to identification, including historical, cultural, professional and personal. These videos can be checked out as a set or individually, and would be excellent for a staff training seminar or as a "refresher" to FAS 101 training. To check-out, please contact the Office of FAS.

Teams Begin Reporting Diagnostic Data

The Office of FAS is happy to report that six of our multidisciplinary community teams have submitted client diagnostic data for June 2000 through July 2001. This first data collection shows that community teams completed FASD diagnoses for 121 individuals during the first year of providing services in their respective regions. It's important to note that the actual number of people served by the teams during this time is actually greater than this number since the Office of FAS requires that only completed cases be reported.

This initial data was analyzed and provided to team coordinators at a team meeting held in conjunction with the FAS Summit in November. As a result of this discussion and the team's input, the data collection instrument is being revised to provide for greater clarity, accuracy and usability. The team coordinators also provided excellent insight that may help to explain some of the variation found in this first set of data. An overview of this first data run and specific findings are included in our 2001 FAS Status Update, available by contacting the Office of FAS.

FAS Dates to Remember

January

25–26, Friday-Saturday: Step by Step-Trying Differently-Not Harder-With the Fetal Alcohol Affected Child. Deb Evensen, presenter, Seward. (907) 235-6735 or (907) 262-6331.

February

6, Wednesday: Fetal Alcohol Exposure and Brain Function: An Overview of the UW Diagnostic Process, Anchorage. Registration closed. (907) 465-3033 or (877) 393-2287.

16–22, Saturday-Friday: 11th Annual Alaska Statewide Special Education Conference, “Joining Hands, Moving Forward,” Anchorage. www.logisticsllc.com/assec/ .

March

4–6, Monday-Wednesday: The Early Years, The Critical Years II: The Science of Early Childhood from Birth to Eight, Anchorage. (907) 269-7801.

April

4–6, Thursday-Saturday: Weaving A Circle of Care 2002 Conference, Anchorage. (907) 279-1799 or (800) 478-7307

May

6–8, Monday-Wednesday: Northwest Pacific Rim 28th Annual School on Addictions: Serving Diverse People, Anchorage. (907) 770-2927.

8–10, Wednesday-Friday: Yukon 2002 Prairie Northern Conference: A Lifetime of Solutions, FAS, Whitehorse, Yukon. (867) 667-3010.

October

7–9, Monday-Wednesday: 2002 Alaska Children’s Mental Health Conference: Ways to Care: Our Journey Ahead, Anchorage. (800) 770-1672 or (907) 451-5045.



Department of Health and Social Services
Office of Fetal Alcohol Syndrome
POB 110609
Juneau, Alaska 99811-0609

www.hss.state.ak.us/fas

DRAFT-Tues, Jan 16A